

# THE FAMILY ADVOCATE™

## A GUIDEBOOK TO SPECIAL NEEDS PLANNING

Designed to educate families on what they need to do to secure their loved one's future.



A SPECIAL NEEDS  
PLAN™

# Inspiration Behind This Guidebook

Planning for the future is challenging. Over the years of serving families, we've learned that many families do not know where to turn for help.

- 65% of parents/caregivers report that they don't have enough help in planning for the future<sup>1</sup>
- 93% of parents/caregivers have not spoken to a financial professional **trained** in special needs planning.<sup>2</sup>
- 56% of parents/caregivers of a child with special needs are unaware of specializing professionals who can help.<sup>2</sup>
- 94% do not have an up-to-date Life Care Plan (i.e. a Special Needs Plan)<sup>2</sup>

<sup>1</sup>The Arc "FINDS Survey 2011"

<sup>2</sup>Easter Seals Study, 2008 and 2010



# *What is Special Needs Planning?*

Special needs planning is a process that identifies the financial, legal and lifetime needs for you, your family and your loved one.

For most families, this process will include discussion of:

- Wills
- Trusts
- Guardianship
- Education on Government Benefits
- ABLE accounts
- Defining your vision for your loved one's life
- Ensuring proper care-giving
- Providing resources for your loved one's lifetime
- And more

Special needs planning does not end with the identification of these needs, but includes the necessary action steps that you need to take to ensure a bright future for everyone in your family during three distinct times of your life:

- 1. While you are alive and well.**
- 2. While you are alive, but are no longer able to be your loved one's primary caregiver because of your own health issues.**
- 3. When you pass away.**





# *Most Common Misconceptions About Special Needs Planning*



## **A SPECIAL NEEDS TRUST IS SPECIAL NEEDS PLANNING.**

Unfortunately, many families believe that by having a special needs trust they've completed special needs planning and they have everything needed to provide a secure future for their loved one. This one myth is potentially the most dangerous because it can provide a false sense of security. A special needs trust is a critical component to special needs planning, but it's only one component of the plan for your family's future.

It is critical to understand the following items in conjunction with a special needs trust:

- How is the special needs trust tied to your financial plan?
- What type of special needs trust did you create?
- Can extended family, like grandparents, leave money to the special needs trust you created, or do they have to setup their own?
- Did you communicate with extended family regarding the details of the special needs trust?
- Does your trustee know the distribution rules of a special needs trust and how to ensure future government benefits are not interrupted?
- Do you know which assets are the most efficient to leave in the trust in terms of taxation and market strategies?



*The best way to get  
something done is to begin.*



## GOVERNMENT BENEFITS ARE ENOUGH TO SUPPORT MY CHILD FOR THEIR LIFETIME.

Government benefits are critical resources that help to offset daily living expenses and a lifetime of medical care; however, they rarely provide 100% of support. Government benefits vary and have complicated rules and qualification requirements. The granting of benefits can depend on the situation of your loved one as well as your own. It is important that you plan beyond government benefits, and understand the costs that are not covered, so that you can build a strategy to provide for those needs.

**"I wish someone would educate parents that government money does not pay for all their child's future needs, and they should, if possible, have additional resources available for their loved one's future."**

**- Residential Housing  
Provider Executive**



## I CAN ALWAYS MAKE DECISIONS FOR MY LOVED ONE.

Many parents believe that, as parents, they are able to always assist with legal decisions in their child's life. This is simply not true. Once a child reaches the age of 18, they are seen as an adult by the legal system, and therefore competent to make all decisions (including financial and medical) on their own. A parent has no legal authority to continue to make decisions and guide their child at that time. If your loved one needs you to continue to make those decisions beyond age 18, you will need to take action and become their legal guardian.





## 4 GUARDIANSHIP IS IRREVERSIBLE.

Guardianship (Conservatorship in some areas) is used by many families to protect their loved one, and to help them with decisions surrounding healthcare and their money. The guardianship process requires that your loved one is deemed incompetent to make decisions by the court. Considering your loved one incompetent can be difficult, especially if your child is “high functioning.” Keep in mind that Guardianship can be reversed; although, the process can be difficult. Depending on your child’s abilities, you may want to consider alternatives to Guardianship.



## 5 I NEED TO HAVE ALL THE ANSWERS BEFORE I START PLANNING.

This is a huge misconception and one that paralyzes many families. One decision that continually stops families from beginning the planning process is, *“Who will care for my loved one when I cannot, or when I die?”* This can be a terrifying decision for many parents; however, a qualified special needs planner has the tools to assist in answering these questions as your comprehensive special needs plan is assembled. A proper planning process will help you find answers and solutions to your questions, as well as bring questions to the forefront that you may have never considered.





## MY CHILD IS ONLY 4 YEARS OLD ... I CAN WAIT TO PLAN.

At four years old or thirteen years old, you may not know the exact trajectory of your loved one's development. In the early years, most parents are focused on doing everything possible to improve the abilities and strengths of their child, and rightfully so. As we all know, tomorrow is not guaranteed, and yet for most of us tomorrow will come and so will the day after. However, the possibility exists that you will not be here tomorrow to care for them, to bring them to therapy, doctor appointments, school, activities, and to financially provide. If you are not here to provide, then who will? How much will it cost? How will it be paid for? These are questions that a qualified planning process will help you answer. When you finish the planning process you will know the necessary action steps that will secure your loved one's future.



*Waiting is a trap. There will always be reasons to wait... The truth is, there are only two things in life, reasons and results, and reasons simply don't count."*

*-Robert Anthony*



## I DON'T HAVE ENOUGH MONEY TO EVEN WORRY ABOUT.

You may have heard someone say, "You don't know what you don't know." Special needs planning is different, because what you don't know can have a severe impact on your loved one's future. Government benefits are available for your loved one but only if they qualify. Some government benefits (SSI and Medicaid) are financially needs based, meaning your loved must remain below an income threshold, as well as an asset threshold. In 2019, if you leave your child more than \$2,000 in an account, they will lose access to the resources that SSI and Medicaid provide. (Certain exceptions to the \$2,000 level exist). It is important to understand how much money is too much money.



# *The 10 Most Common Mistakes You Need to Avoid*



## **NEVER DEFINED FUTURE NEEDS OF YOUR LOVED ONE**

If you have a GPS system, you know that if you want directions, you must enter your current position as well as a destination. If you never enter a destination, the GPS system can't help you. The same can be said for your loved one's future needs. You must first take time to program the GPS, meaning define the future needs of your child (i.e. therapy needs, housing, care-giving environment, monthly expenses, medical needs, employment). Second, pinpoint your destination, meaning define a lifetime cost for your loved one's needs. In this way, you will know how much money it will take to provide these future needs.



## **NEVER SET UP WILL OR OTHER LEGAL DOCUMENTS**

A Will does three important things for you, your family and your loved one. It tells the court system:

1. Where your property goes
2. Where your people go (who will be future care-givers)
3. Who will Administer your Will (Executor/Executrix)

Without a Will the court will make these decisions for you. Your loved one may not receive the assets you would like, or your loved one may receive assets that could result in the loss of eligibility for government benefits. Furthermore, the court can decide where your loved one lives and he or she may not be cared for by those you intended.





## USE DISINHERITANCE MODEL

**"We will just leave all of our assets to other children or to a family friend and they will see to it that our loved one will receive the proper care."**

This has been a common planning method that carries unnecessary risk. For instance, when we leave money to another person, that money is now their asset to do with as they wish. They can decide to skimp on care for your loved one and use more of it for themselves.

Another risk we take with this model is liability. For instance, if the person we leave the money to ends up divorcing in the future, then 50% of the money intended for the care of your loved one can be given to the ex-spouse in the divorce settlement. Another risk can occur if the individual you leave the money to has financial difficulty (bankruptcy) or is named in a lawsuit; then the money you intended for the future needs of your loved one may be wiped out. There is a much better way to protect the needs of your loved one, and it is setting up a special needs trust.



## SPECIAL NEEDS TRUST IS NOT SET UP OR THE EXISTING TRUST IS NOT APPROPRIATE

A Special Needs Trust is a uniquely designed trust for you to leave assets that will provide for your loved one's future care. By placing them in this unique trust, you will avoid the dangers of the previous mistake. Furthermore, you will protect eligibility for government benefits such as Medicaid and SSI.

### Words of Caution

*A Special Needs Trust is not a regular trust. You need to meet with a qualified special needs planner and qualified attorney to ensure you have the right type of trust.*





## NEVER CHANGED BENEFICIARY DESIGNATIONS

Beneficiary designations are most notably found on life insurance and retirement plans such as a 401(k), IRA, Roth IRA, pension plan, etc. These are important because the beneficiary designation overrides the sentiments of your will. Make certain to designate the proper primary, secondary and tertiary beneficiaries to ensure your money goes where you intend.

### A CAUTIONARY TALE



A father visited an attorney to draft a special needs trust so that he could protect his son's future and secure his son's future government benefits. The attorney designed, created, and drafted a special needs trust using the proper language with all the necessary provisions. They named a family member as a trustee. They even named a corporate trustee to handle the administration of the trust, making sure it will always stay qualified as a special needs trust even if the government benefit landscape changes. The trust was well thought out and brilliantly designed.

The father felt very secure.

The father died.

All his assets were transferred to the special needs trust for the benefit of his son. All his assets except for an old IRA. An IRA is an account that does not pass through the Will, but instead passes through the beneficiary designation. This father never changed the beneficiary designation after his son's trust was created. The IRA beneficiary was his son! This means that the IRA passed directly to his son, and because this retirement account had a value of \$85,000, his son lost all his government benefits. Everything this father was trying to avoid happened because a small detail was not completed. He never integrated his accounts and there was never any coordination.





## NEVER SECURED YOUR OWN FUTURE

If we imagine your life as a truck rolling down life's highway, then your child's life would be represented as the trailer being pulled by the truck. Your child's future is hitched to your well-being and to your successful future. The future of your child is contingent upon your own. If your truck breaks down, then in essence, so does the trailer.

As parents, we are always putting our children's needs before our own and working diligently to create a bright future for them. Your child's future is only as healthy as your own. As you begin planning for the future of your child, you must also plan for your future. By securing your future, you also help to create a better future for your child.





## DON'T UNDERSTAND THE TAX SYSTEM

The tax system can be complex to understand for any family; however, it is much more so when you are trying to provide for a lifetime of support for a loved one with special needs after the parents are gone. Special needs trusts are a great tool to use in order to provide for this support. As families plan, however, it is critical to understand the tax implications of different assets when they are held in a special needs trust. You'll want to work with a qualified professional that can help you begin funding accounts in a way that minimizes taxes and maximizes the amount that is passed on to your loved one.

### TAX RATES— INDIVIDUAL VS. TRUST

2020 – Top Tax Rate for Individuals is 37%, but that only impacts married taxpayers with incomes higher than \$622,050\* and single tax payers that earn over \$518,400\*. The top tax rate for Trusts is also 37%, but it reaches that level with \$12,950\* of income. This means that an old 401(k) or IRA that has never been taxed, will be taxed as income tax when it is distributed from the trust, meaning a higher income tax rate is likely to be assessed. Therefore, it is crucial to know what types of assets should be put into a special needs trust.

\*Based on projected 2020 rates. Subject to change.



## NEVER MADE FUTURE CARE-GIVER OFFICIAL

Either you never chose a future care-giver, or you did choose one but never put it in a will. By placing those directions in your will, it provides the court system guidance regarding the future care-giver.

This is usually one decision that is very difficult to make; however, a qualified planner should have the tools necessary to help you in making this decision.





## **COMMUNICATION IS ABSENT**

It is common that parents and caregivers do not take the time to document their child's medical history, daily activities, therapists, schools, professionals involved in their child's life, organizations they are a part of, their child's favorite things (i.e. music, movies, books, blankets, toys, activities, etc.), behavioral issues, sensitivities, diet, and most importantly the hopes and dreams for their loved one's future. You have learned quite a bit about your child and how he or she interacts with the world, and we want to ensure the next caregiver is given a head start so they can provide the best care possible for your child when you are no longer able.

It is critical that you share your plan with extended family. It is all too common for parents to do planning in a vacuum. This can be a problem when a well-intended grandparent leaves money for your child. A gift could disqualify your child from future government benefits which would result in the loss of hundreds of thousands of dollars of benefits over your child's lifetime. This event can be avoided by sharing your plan.



## DID NOT INVEST IN YOUR PLAN



**In order to assemble a proper plan, it will take an investment of 3 things:**

- 1. Time**
- 2. Money**
- 3. Education**

Take the time to learn as much as you can about special needs planning, and invest in finding a professional that specializes in working with families that have special needs. (We provided interview questions to help you find qualified professionals on **page 16.**)

Generally, there is a cost to designing, creating, and implementing your plan to ensure it will work from year to year. You can find additional resources online at **[www.ASpecialNeedsPlan.com](http://www.ASpecialNeedsPlan.com)** that will help you in continuing your education on special needs planning.

When you are ready to begin your plan, we are here to be in service to you and your family.

*“Form your purpose by asking for counsel,  
then carry it out using all the help you can get.”*

*Proverbs 20:18*



## A CAUTIONARY TALE

The grandparents of two siblings with autism passed away and left them more than \$250,000. The children's parents decided to set up a Special Needs Trust for this money, and enlisted the help of a financial planner and an attorney who were not experts in this specialized area. Later, the parents decided to use some of the trust money to build a pool. They consulted with their attorney and financial planner to make sure they were following the distribution rules. Because the pool was used for the children's therapy needs, the purchase qualified. They asked these advisors if they could also build a pool house or cabana. The advisors said yes.

The government later audited their trust. Unfortunately, the cabana was not considered necessary for the therapy needs of their children. The trust was disqualified as a special needs trust. What did this mean? The parents lost their children's government benefits. Not only that, they had to repay the government for all benefits provided since the date the trust was first created. And that large inheritance from the grandparents?

Completely gone.



# *Interviewing Professionals*

Finding a qualified and trained professional in special needs planning, including financial planners, attorneys, trust companies, and accountants, is vital in securing your plan. We've assembled a list of questions you can ask to aid in choosing the right one.

1. I know this is a highly specialized area that requires knowledge of government benefits, the legal system, tax code, distribution planning, and transfer of assets from one generation to the next, do you have expertise in these areas? How would I know that?
2. What professional training have you had in the area of special needs planning? What courses have you taken? Can you show me your most recent course manual? Can you share with me the books you have read on special needs planning?
3. Do you attend continuing education conferences on the topic of special needs planning? If so, how often? If not, how do you stay on top of the changes in the legal system, tax code, government benefits and their impact for special needs families?
4. When you're considering the distribution phase of our money and the transfer phase of our money, how do you ensure our money gets to our child after we are dead? What do you do to limit the erosion of these assets to taxation?
5. What is the maximum asset limit in order to qualify for Medicaid?
6. What is the difference between SSI and SSDI?
7. Can you explain the advantages, as well as the drawbacks, to an ABLE Account?
8. Can you clearly define the planning process you use to help me secure the future of my loved one with special needs? *(The professional should be able to easily describe the steps they use in serving families.)*



9. Can you provide me 3 families that you have helped in the area of special needs planning, so that I may call them to discuss their experience?
10. Can you provide me the names of 2-3 professionals you work with in the area of special needs planning?
11. Who do you turn to when you have questions in the special needs area?
12. Are you involved in the special needs community? If so, how? (This question will show you if the professional has his/her finger on the pulse of the special needs community by their involvement with organizations, societies or conferences. It will also show empathy and support for the community as a whole.)

When interviewing them, stay focused on their mannerisms. If the professional you are interviewing is able to answer these 12 questions with authority and you receive positive feedback from the families and professionals you contact, then you have found yourself a highly qualified special needs planner. You should move quickly to hire them.

With their help, you will begin a journey that will lead to security for you, your loved one, and your entire family. The planning process you go through will provide you answers to many questions, including, ***“What happens to my child when I am no longer able to care for them or when I die?”*** Having the answer to this question should release a burden from your shoulders, and should provide peace of mind.

# *Understanding the ABLE Act*



**The ABLE Act**, also known as **Achieving a Better Life Experience Act of 2014**, allows individuals who were deemed disabled before the age of 26 to save money in specific accounts and not jeopardize necessary government benefits. Before the ABLE Act was passed, an individual with a disability who relied on government benefits, like SSI and Medicaid, could not save more than \$2,000 without losing all their benefits; therefore, impacting housing, employment, transportation and more.

The ABLE Act will provide individuals with a disability the right to save money. The ability to work and save money provides a deep feeling of accomplishment, confidence and success. These feelings will help those with disabilities reach levels of independence not seen in the past.



At this time, the ABLE Act includes some drawbacks. For the majority of families, these accounts do not lend themselves to be the primary account for parents and relatives to save money for the future support of their loved one.

For most families, these accounts will not replace other lifetime planning tools such as a Special Needs Trust because of the following drawbacks:

- Annual funding limitations based upon the annual gift tax exclusion amount (the 2019 limit is \$15,000).
- Maximum account value of \$100,000 before SSI is suspended (a monthly income used to fund housing and other necessary life-long supports).
- Payback Provision to Medicaid at the passing of the individual with the disability. This provision means that any remaining money in the ABLE Account, at death, will be susceptible to government payback.
- Individual must be diagnosed with a disability, that meets SSI program standards, before the age of 26.

*Remember that with any planning tool, it is important to understand how to best use the ABLE Account for your family's specific situation before jumping in!*



## *A Promising Plan*



One family had two children, including a son and a daughter. Their daughter was diagnosed with a disability that would make her unable to care for herself throughout her lifetime. Like many families, most of their time was taken up in managing their daughter's needs, schooling for both the children, and the ordinary activities of family life.

The couple's savings were mostly in their 401k with a small portion going to an investment account. They had insurance through work and additional insurance they purchased on their own, but they did not know if it was the right type of insurance or if it would be enough to provide for their son and certainly not sure if it would be enough to provide for their daughter's lifetime care needs.

They had a will that established a Testamentary Trust (created upon the parent's death) for each child. While there were provisions for a Special Needs Trust to be created within the parents' will, the parents did not know how or if taxes would impact the amount of money their daughter would ultimately receive. Furthermore, Government Benefits were a critical element for their daughter, but they did not know how they could be integrated into their long term plan.

Additionally, the parents were never advised to create a Communication Plan, which would have led to conversations to identify any planned gifts to the children. They felt there just wasn't enough time to stop and determine their children's future needs.



The parents were introduced to a team of Chartered Special Needs Consultants™ at A Special Needs Plan, who were experts in working with families that have loved ones with special needs.

After meeting with them, they were able to coordinate the complex financial, legal, government benefits, communication and tax strategies into **one plan** that aligned with the vision they had for the future of their family.

They **identified** the amount of resources their daughter would need for her lifetime. They received education on how their insurance plan needed to be adjusted to meet these needs.

Next, they reviewed and reworked their wills. They established an **Inter Vivos Special Needs Trust**. They learned about the tax impact of the assets inside a Special Needs Trust and were able to adjust the assets that should be included in the trust, which resulted in **avoiding a 40% tax**.

Following, they built a **Communication Plan** and setup conversations with family relatives. They learned that the grandparents had created an account for their daughter and the father's sister had named their daughter as a beneficiary on an account. These acts of generosity could have caused the daughter to lose her government benefits. They provided their family members written steps to change all gifts to funnel through the Inter Vivos Special Needs Trust so their daughter could receive the gift without losing other important benefits.

In the end, after working with A Special Needs Plan, the family had a **coordinated strategy** that provided adequate resources for their son's needs and for the lifetime care of their daughter. It gave them **peace of mind** knowing there was a plan in place to get them from where they are to where they want to be.



# About Us

We have served over 12,000 families through education, planning, and continued support since 2005. Our team consists of highly trained Chartered Special Needs Consultants.

We are A Special Needs Plan™.

## WE OFFER

- Planning consultations to families
- Educational workshops and seminars for families, organizations, and financial professionals
- Special needs planning educational resources

## OUR PURPOSE

Everything we do is for serving families by building Lasting Independence for Everyone (LIFE). This includes a better life for those with Special Needs, peace for parents, and security for siblings.

## CORE VALUES

Serve • Lead • Support • Celebrate • Truth

## MEET OUR FOUNDER

Ryan Platt, founder of A Special Needs Plan, completed his Special Care Planner Certification in 2005 at the American College in Bryn Mawr, PA, in which he received advanced training in estate and tax planning, special needs trusts, government programs, and the emotional dynamics of working with families with loved ones that have special needs. In 2013, he went on to complete the Chartered Special Needs Consultant™ designation.



Ryan's unwavering commitment to helping individuals with disabilities and their loved ones has helped people locally, regionally, and nationwide better understand life care planning while raising awareness about honoring individuals with special needs.



# Helping You Take Action

Start a personal planning relationship with one of our highly trained special needs planning professionals.

You can also invite Ryan to speak to your national and state conferences, as well as local workshops.

You can begin by calling, e-mailing, or visiting us on the web.



**(704) 326-7910**



***info@aspecialneedsplan.com***



***www.ASpecialNeedsPlan.com***

## Notes For Your Plan

*"Careful planning puts you ahead in the long run; hurry and scurry puts you further behind." Proverbs 21:5*

MAY THE ROAD RISE TO MEET YOU,  
MAY THE WIND BE ALWAYS AT YOUR BACK,  
MAY THE SUN SHINE WARM UPON YOUR FACE,  
THE RAINS FALL SOFT UPON YOUR FIELDS,  
AND UNTIL WE MEET AGAIN,  
MAY GOD HOLD YOU IN THE PALM OF HIS HAND.



*We thank you for reading The Family Advocate.  
It is our sincere hope that it is a helpful tool for  
you and your family. All of us at A Special Needs  
Plan wish you, your family, and your loved one,  
all the best! Please know we are here to help.  
-A Special Needs Plan*

Disclaimer: The information provided in this guidebook is general in nature. It is designed with the understanding that Ryan Platt is not rendering any legal, accounting, financial or other professional advice. This information should not be used as a substitute for professional service in specific situations. If legal advice or other expert assistance is required, the service of a professional should be sought. By reading this information, you agree not to hold Ryan Platt or A Special Needs Plan liable for any decisions you make regarding your planning strategy. CRN202102-243645  
© A Special Needs Plan, Inc. All Rights Reserved.